

Person To Person

“In the real world, people learn from each other, help each other, and protect each other. In the field of mental retardation, one must be licensed to reach, certified to treat, and commissioned to protect.” (Blatt, 1981, p. 345)

Over the years our service system has evolved into one which tries to meet an ever increasing variety of people's desires for supports and outcomes. Unfortunately, this has led to a system that frequently ignores the other, non-specialized, resources that are available to all citizens in their communities. The current system is built upon assumptions that people need ongoing services and they are therefore often enrolled in programs that provide more services than they actually need or want. In order to take advantage of the services and supports available outside of social services systems a different way of helping people think about what they want in their lives is needed.

Person to Person is an attempt to broaden the Division of Developmental Disabilities approach to assisting people and families identify what supports they would find most helpful, and identify potential sources of those supports. This approach should result in people being less dependent on formal, specialized services, and becoming better connected to informal and generic supports in their communities. Sometimes this means rethinking who is being supported, the person with a disability and their family, or their neighbors, coworkers, bus drivers, restaurant services, and other members of their communities. Assisting other members of a person's community to include them sometimes supplants specialized social services, and the person with a disability receives assistance in locating those supports. The role of Person to Person becomes one of assisting people to find those other sources of support wherever they exist, not creating specialized services for the supports a person wants. The crucial outcome should be "... a personal network of family, friends, coworkers and community members" (Nisbet, 1993, p. 3), that may supplement, or even supplant more traditional disability services.

Listening to People and What Supports They Want

Person to Person is based upon the belief that listening to people and their family and friends, is the key to knowing how best to help. Listening means adopting a different perspective than has been offered through traditional planning processes. At the core of this different perspective are the processes embodied in person centered planning approaches. Some names associated with person centered planning include Lifestyle Planning (O'Brien, 1987), Personal Futures Planning (Mount & Zwernik, 1988), MAPS and PATH (Forest & Pearpoint, 1992), and GAP (Beach Center on Families and Disabilities, n.d.). All of those planning procedures share some common characteristics, which are defined in the following section.

The information to develop a plan for a person's desired future and the supports they want can be done in a variety of ways. Sometimes a person centered planning process is a good choice. Sometimes it is much more than a person needs. Often spending time with the person, or the person and one or two allies (who may be family members), is enough to elicit the information needed to formulate a plan for the support the person wants. This information can be gathered over a period of weeks by spending some unstructured time with the individual and their closest allies. It is also likely for some people that not all of the areas mentioned below under Listening to Desired Futures are ones in which support is desired. Many people may have a single area or theme that is currently causing them to seek support, e.g., social relationships, or contributions.

Listening to people usually consists of three major areas; (1) understanding the person's past, his/her history; (2) developing a personal profile that describes the person; and (3) understanding where the person wants their life to go, now, and in the future.

Personal history – comes from the individual, his/her family, closest friends and allies and past service providers. Focus is on important milestones in the person's life, major events and defining moments, cultural dynamics, and other events or people who had a major impact on the individual's development, values, beliefs and personal characteristics.

Constructing a person profile – this entails asking questions about all or some of the following:

Relationships – who are the important people in the individual's life?

Places – where does the individual spend time?

Preferences – what places, people, things, and activities does the person enjoy?

What works – how does the person prefer to be treated by others? Are there certain styles of interaction that create interest, excitement or enthusiasm? Are there certain places and activities that generate a positive experience for the person?

What doesn't work – creates feelings of frustration, anger, fear or avoidance?

Choices – how, when, and where does the person exercise autonomy in their life?

Gifts, strengths, capacities – what is the person particularly good at, what do other people like about the individual, what contributions might they offer to others?

Listening to Desired Futures – this entails hearing how people, and/or their closest allies (which may include family and friends), see the future unfolding for the person. What are the most important aspects of the future for this person, what are the “non-negotiables,” e.g. things the person absolutely must have to reasonably construct a satisfying life? What things are highly desirable, e.g., second only in importance to the non-negotiables? What other things are strong preferences that the person would like to be part of their lifestyle? Finding these things out can be enhanced by focusing on areas like those in the Residential Services Guidelines.

Community presence – where does the person want to: live, recreate, volunteer, work, engage in associations with other people?

Making contributions – how does the person wish to participate in the life of the community by offering their contributions to others in the community? What work would the person like to do? Volunteering? Participate in school or classes to enhance their contributions? Does the person have artistic gifts to offer others? How would the person like to participate in civic activities?

Self-determination – how will the person exercise control over their life? How will they choose where to live and with whom? How will they decide where their supports come from? In what way will they choose the people who will be a part of their life? How will the person make financial decisions? Acquire and care for personal possessions? How will the individual determine the rhythm and routine of their life? Will the person be able to make “bad” choices but learn from them, without undue interference from others?

Relationships – What opportunities does the person need/desire to establish new relationships or maintain old ones? How does the person work out issues of reciprocity with members of their social network? What kinds of relationships does the person desire, close friends, acquaintances, intimate partners? How does the person want to balance their relationships with a need for privacy?

Competence/abilities – In what ways does the person want to achieve success in preferred or necessary activities? To what degree do they wish to learn new skills? Which ones? What outcomes do they prefer to meet through personal support strategies, e.g. van for mobility as opposed to transit, buying laundry services as opposed to doing it themselves? What technology or equipment does the person feel would enhance their competence or abilities? Can natural supports assist the person's desire for enhancing their competence or abilities?

Health and Safety – how does the person wish to access needed medical services? Does the person want access to counseling? Does the person need/want access to nutrition and dietary service or support? How does the person like to exercise? What environmental risks is the person willing to tolerate or must avoid, e.g. neighborhood safety, noise, pollution, secondary smoke? How will the person balance, or get support to balance, safety and health risks against short term enjoyment, e.g. smoking, lack of exercise, alcohol consumption, etc.?

Not all areas are of equal concern or interest to all people. Sometimes a person is primarily interested in only one area or theme in their life, e.g. a job, or relationships with other people. Sometimes a person may be interested in discussing all the areas mentioned above, and then choose to focus on only one or two areas at any given time. Respect for the areas in which people do not wish to have assistance is just as important as hearing the areas in which help is desired. Lastly, people have the right to change their minds over time. Person to Person should be flexible in accommodating those changes.

Helping People Make Connections

Once a person's vision is articulated, identifying the supports to move closer to that vision becomes the focus. Often a good first step is to construct an inventory of what is already available as resources to the person. What relationships already exist that could further the person's desires for their life? What current friends, family members, neighbors, community associations and service agencies are part of the person's life? Sometimes formulating the plan itself is all that a person needs to gain access to their desired outcomes. The plan, having identified the outcomes and current resources, serves as the basis for improved coordination of those resources or points the direction in which they should be used.

Another level of help is gaining information to be used in support of the person's plan. Once again, for some people, this is sufficient. Many times people, or their family, friends or allies, have adequate resources to achieve desired outcomes once they are given information about how to do so. Sometimes people only need information on how, or where, to gather additional resources.

Finally, another level of support that stops short of offering what we might think of as traditional DDD services, is to find ways to help people get connected to other needed resources. This would be the case where people wanted to be connected to some form of natural supports to gain access to those resources needed to work toward their desired future. Many times people may desire outcomes that other people, natural supports or generic community services, can offer better than the DDD or a social service system. For example, many people desire to have more people in their lives upon whom they can depend for companionship, emotional supports and feedback about their personal lives. Those kinds of supports are best delivered by friends, family, and other members of one's social network, not from paid services providers. In those instances natural supports are not only preferred over paid supports, they are absolutely indispensable to satisfactory achievement of people's desired vision for their lives.

In general, it is desirable to receive supports from (1) family/friends, neighbors, coworkers, classmates, etc.; (2) generically available informal supports in the community, such as churches, private organizations and associations like bicycle clubs, political interest groups, etc.; (3) generically available civic supports in the community like community colleges, neighborhood councils, etc.; (4) generically available paid supports in the community which are available to all community members including goods and services from people such as servers in restaurants, clerks in supermarkets, personal counselors, tellers at banks, etc. Other supports may, at times, be necessary from governmental agencies (SSI/SSA, employment security, food stamps, etc.). Lastly, at least for the time being, it may be that a person, or their family, is still interested in and can benefit from some form of specialized services from the DDD system.

Natural supports means using the same methods and sources to solve problems, complete activities and achieve desired lifestyle outcomes as other members of the community. This entails utilizing those supports without direct assistance from the paid DDD social service system. Once again, Person to Person may be thought of as

offering support not only to people with disabilities, but equally so to other members of the community so that they may recognize and accept the contributions of people with disabilities. While we may initially think of places where connections can be made, it is the people who we find in those places that constitute the support, not the place itself. Thinking about places where people with interests, values, beliefs and histories similar to an individual with whom one is working can be very fruitful if we focus on the people in those places, not the places.

Kinds of Support People Might Desire

People generally offer social support to each other in a variety of different ways. Not all people are good sources of all kinds of support. However, it may be helpful to think about how support is offered to people.

Planning – helping a person develop a set of strategies to use resources. This can be done by a variety of people and is sometimes sought from people with special experience in helping people develop plans, such as career counselors. Person to Person is, itself, an opportunity for people to get help developing lifestyle plans.

Information – providing an individual with information only about how to go about securing needed supports. This form of support realizes that given the proper information people are often then able to pursue their own course of action.

Learning/instruction – helping a person acquire the skills they need to meet their own outcomes or secure the natural supports to do so. This can mean seeking like-minded individuals who would teach skills to a newcomer (garden clubs, music groups, ethnic cooking clubs) or purchasing skills instructions from other community resources like community colleges, private tutoring or community centers.

Companionship – engaging in activities with the person for no other reason than mutual desires, satisfaction, liking, etc. It is very difficult to see how this can be provided inside a services system. This does not mean, however, that staff and people with disabilities cannot become friends, but other relationships with non-staff are also necessary to insure stability in this area. While friends are our best source of companionship, sometimes attending meetings or joining associations of people who are interested in the same activities (baseball, music, gardening, hiking, etc.) can be sources of companionship.

Emotional support – help making crucial decisions, support in crisis, support during loss, grieving, etc. Here again, system support is typically not a good answer. While people paid to provide supports can be loving, caring and dedicated people their stability in the lives of people with disabilities makes dependence upon them for emotional support at best a risky proposition.

Feedback – information about how a person is perceived by others, may relate to behavior, attitudes, dress, appearance, etc. This form of support is usually most highly

valued from people we trust and respect. Trust and respect come over time and is typically a mutual situation.

Financial – support in the form of direct monetary award, cancellation of part, or all, of a financial responsibility, or payment of a financial responsibility for a person.

Person to Person's Underlying Principles and Beliefs

Uses a Variety of Methods – not everyone needs, or wants, a full, formal person centered plan, or an ongoing circle of support. Both of these services/supports entail a fairly intensive effort to help people discover what they want and support their ongoing efforts to achieve certain goals in their life. Sometimes, though, it may only be necessary to talk with the person, and perhaps one or two family members or friends, to arrive at an understanding of the most important things a person needs to fulfill their life goals. The more formal and extensive lifestyle planning and circles of support are frequently, but not always, chosen when the following situations exist for a person: (1) facing major transitions in life, e.g. leaving school, moving to a new town, loss of personal support through death or another person's moving, etc.; (2) facing a major life crisis, e.g. behavioral issues, issues of medical or physical support, loss of a job, etc.; (3) suffered a major loss in life, e.g. losing friends or loved ones; (4) when significant conflict has arisen over the elements of services and supports a person's wants; and (5) when all previous efforts have failed to identify what things are most important in the person's life. Many people, however, only need help finding a roommate, locating sources of financial assistance, or ways to seek employment. Since our service system has been based, in large part, on serving people with more extensive needs, there may be a tendency to help more than is really necessary. It will be very important to strike the appropriate balance between helping and unnecessarily intruding.

Focuses on strengths – helping people decide what they most want or need should be a positive enhancing process, as opposed to deficit seeking.

Recognizes people's ownership of their lives and the planning process – the process by which a person discovers and articulates their lifestyle goals belongs to the individual, not any element of the service delivery system.

Blends formal and informal supports – the planning process should seek a mixture of formal and informal supports to help a person achieve their lifestyle goals, with a preference given, where possible and appropriate, to informal supports. Informal supports are favored due to their flexibility and lower levels of intrusion into people's lives.

Relies on a large and diverse social network – no one person, or set of people, can meet all of the lifestyle needs or desires of another person. Having only one or two people or agencies to go to for support results in dangerous levels of dependence on those people or agencies. The more connected people are to a network of people ranging from acquaintances to close friends, the less likely they are to lose crucial support if someone leaves the network for whatever reason. Being connected to a

broad network of people also brings a degree of safeguards into the person's life not possible when only paid service people participate in planning and delivering services to people.

Based on the person's preferences, desires and vision of their future – this again implies the person is in charge, sometimes with the help of their family, closest friends or allies, in determining what is most important. This means listening carefully to what a person, or their allies, are saying, and acting on those messages.

Planning participants must know the focal person well – only people who know the individual and their preferences, style of communication, etc. can be effective participants in the planning process. This is especially important when the person has difficulty conveying their preferences due to communication barriers.

References

Beach Center on Families and Disability (n.d.). How to make positive changes for your family using group action planning. Lawrence, KS; Beach Center on Families and Disability.

Blatt, B. (1981). In and out of mental retardation: Essays on educability, disability, and human policy. Baltimore: University Park Press.

Forest, M., & Pearpoint, J. (1992). Families, friends and circles. In J. Nisbet (Ed.) Natural supports in school, at work, and in the community for people with severe disabilities (pps. 65-86). Baltimore: Paul H. Brookes.

Mount, B. & Zwernik, K. (1988). It's never too early, it's never too late. A booklet about personal futures planning. Minneapolis: Metropolitan Council.

Nisbet, J. (Ed.). (1992). Natural supports in school, at work, and in the community for people with severe disabilities. Baltimore: Paul H. Brookes.

O'Brien, J. (1987). Lifestyle planning. In B. Wilcox, & G.T. Bellamy (Eds.). A comprehensive guide to the activities catalog (pps. 175-189). Baltimore: Paul H. Brookes.

Resources

For more information on planning processes contact:

Personal Futures Planning – Communitas Inc., P.O. Box 374, Manchester, CT. 06040,
(203) 645-6976

Essential Lifestyle Planning – Michael Smull, University of Maryland, 630 W. Fayette
St., Baltimore, MA (410) 706-2140

MAPS and PATH – Inclusion Press, 24 Thorn Crest, Toronto, Ontario, Canada
M6H2S5 (416) 658-5363

GAP – Beach Center on Families and Disability, 3111 Haworth Hall, University of
Kansas, Lawrence, KS 66045-0001 (913) 864-76--